



When a Loved One Needs Care: Navigating the Long-Term Care System

Making the decision to move into a Nursing or Adult Care Home is one of the most difficult tasks a family ever faces. But when it becomes necessary, prospective residents and their families should have the best information possible to make this decision. This handout is designed to walk you and your family through the process of navigating the long-term care system.

Understanding Medical Needs

If you suspect that a long-term care facility is needed for your loved one, the first step is to have a conversation with the individual's primary care physician. If your loved one is able to be part of this conversation, it is important for him or her to be included and be an active participant in the process. Be sure to provide the physician with a comprehensive overview of the individual's care needs. For example, does your loved one require assistance with personal care such as bathing or dressing? Have you noticed any changes in memory or unusual behaviors? Is your loved one able to walk independently or is assistance needed?



Sometimes the decision to move into a long-term care facility happens after your loved one is hospitalized because of injury or illness. If this is the case, the doctor and social work staff at the hospital will work with the family to arrange for discharge from the hospital to a long-term care facility.

Determining Level of Care

Once the physician has a clear picture of your loved one's needs, he or she can recommend a level of care. In other words, the physician will recommend whether or not your loved one needs a Nursing Home or an Adult Care Home (a.k.a. Assisted Living). Adult Care Homes and Nursing Homes are two terms often used interchangeably, however the two are actually very different, and a person who is a candidate for one is not a candidate for the other. Here are some considerations when determining level of care for your loved one:

- An **Adult Care Home** provides communal living, with planned activities, housekeeping and laundry, transportation, meals, exercise and wellness programs, opportunities to socialize with other residents, and assistance with activities of daily living. Adult Care Home residents are generally healthier and require less hands-on assistance than Nursing Home residents. In N.C., there are two kinds of licensed Adult Care Homes. Family Care Homes are licensed for 2-6 residents. Adult Care Homes are licensed for 7+ residents. The term Adult Care Home is often used interchangeably with Assisted Living or Rest Home.
- In a **Nursing Home**, residents are under the 24-hour care of licensed or registered nursing staff and certified nursing assistants. Some examples of reasons someone

might need skilled nursing would be if they were bed bound, needed a respirator, or had wounds that were not healing and required daily care. Nursing homes also provide rehabilitation to help people gain back their independence after a serious health problem, i.e. a stroke or fall.

- Some long-term care facilities offer **Memory Care Units**. If your loved one has a problem with memory or confusion and is at risk for wandering, you may need to select a long-term care facility that has a special locked unit for people with dementia. These units may be offered in both Adult Care and Nursing Homes. The level of care will depend on your loved one's other medical needs.
- Most Nursing Homes and Adult Care Homes offer only one level of care within the facility. **Continuing Care Retirement Communities (CCRCs)** are different. CCRCs offer levels of care ranging from independent living to skilled nursing care so that, as a resident's health declines, they are able to continue to live within the same community. If you are considering a CCRC for your loved one, keep in mind that these communities usually require that you "buy in" or, in other words, pay a lump sum of money to be able to live there. Then, there is typically a monthly fee similar to rent. Most CCRCs are private pay and a contract must be signed.

Completing the FL2

Once the determination of level of care is made, the physician will complete a document called an FL2. This is a one-page medical form that lists the physician's recommended level of care as well as medical diagnoses, care needs, and medications. Long-term care facilities use the FL-2 form as an evaluation/assessment tool in deciding whether or not their facility will be able to provide the most appropriate level of care.

Assessing Finances

Long-term care can be very costly. Many people think that Medicare or private health insurance will pay the costs, but this is generally not the case. Your loved one's financial situation is going to influence which long-term care facility you ultimately select. Consider this:



- In North Carolina, the average monthly cost of an Adult Care Home is roughly \$3,000.
- The average monthly cost of a Nursing Home is roughly \$6,500.
- These figures do **NOT** factor in medication copays, clothing, personal care items, and other necessities.

Individuals are responsible for paying for their own care to the extent that they have the means to do so. Private Pay is a type of payment where the resident uses his or her own resources to pay for the care in a facility. Private pay means payment is entirely out-of-pocket. Unfortunately, the high cost of long-term care makes paying privately impossible for many people. If your loved one cannot afford the cost of long-term care, you must consider some alternative options:

- **Payment options for a Nursing Home:**

- **Medicare** will pay part of the cost for skilled nursing and rehabilitative services in a skilled Nursing Home (up to 100 days) following a recent inpatient related stay in a hospital. This is typically for brief rehabilitative needs and the individual is responsible for copays after the first 20 days. After Medicare coverage ends, the individual must either pay privately or find an alternative payment source such as Medicaid. Medicare does **NOT** pay for care in an Adult Care Home. Call 1-800-MEDICARE for more information about Medicare coverage in a Nursing Home.
- **Medicaid** may help pay for Nursing Home care, but there are income limits, resource limits, and transfer of asset requirements. Your loved one's income must be less than the cost of care in the facility at the Medicaid rate. Medicaid must approve the need for the level of care. Your loved one must use most of his or her income to help pay for the cost of care. This is called the "patient monthly liability." Medicaid will pay the rest to the facility. Medicaid does **NOT** pay for care in an Adult Care Home. To apply for Medicaid for Nursing Home care, contact your county Department of Social Services.

- **Payment options for an Adult Care Home:**

- **Special Assistance** is a state-funded program that will help cover the cost of an Adult Care Home. The maximum countable income limit is \$1,228.50. The maximum countable income limit is \$1561.00 for residents of Special Care Units. The asset limit is \$2,000. To apply for Special Assistance, contact your county Department of Social Services.
- In some cases, an individual might make a little bit too much money to qualify for Special Assistance but not enough money to pay privately for an Adult Care Home. When this happens, the family must consider the following questions:
 - Does your loved one have any assets that can be sold to help cover the cost of care?
 - Are there enough financial resources within the family to supplement the individual's income to cover the cost of care?
 - Which facilities are the most affordable? This requires calling around and comparing rates. Some facilities are flexible and willing to work within an individual's income. Generally, Family Care Homes tend to be less expensive than larger Adult Care Homes, though not always.
 - Does your loved one qualify for Nursing Home care? Sometimes, a person's level of care is "on the line" between Nursing Home and Adult Care Home. Medicaid for a Nursing Home allows an individual to have a higher income than Special Assistance for an Adult Care Home. In this situation, an individual might elect to move into a Nursing Home rather than an Adult Care Home in order to qualify for financial assistance. However, the person must medically qualify for a Nursing Home – the decision cannot be based on finances alone.

- **Other long-term care payment options:**

- For eligible veterans, **VA benefits** may help pay for long-term care. If your loved one is a veteran, be sure to check with the The Department of Veterans Affairs to see what benefits he or she may be eligible for.
- A **long-term care insurance** policy may help pay for long-term care. If you have a policy, you should contact the insurance company to learn what services are covered before selecting a facility.

All long-term care facilities accept residents who pay privately for their care. Some facilities **ONLY** accept residents who pay privately for their care. Others will accept some of the payment options listed above. Most Nursing Homes accept both Medicare and Medicaid. Some Adult Care Homes accept Special Assistance, but not all of them do. Unless you are certain that your loved one can pay indefinitely with private funds, choose a facility that accepts another form of payment. Understanding the various payment options is a crucial aspect of navigating the long-term care system. Remember that your method of payment will largely influence which home you select.

NOTE: Some attorneys specialize in the area of estate planning and paying for long-term care. To find an attorney in your area, contact the NC Bar Association at 1-800-662-7407.

Selecting a Long-Term Care Facility



Now that you have determined what level of care your loved one needs and how he or she plans to pay for care, you must select a long-term care facility. If you live in an urban area, you may have many facilities to choose from. In a more rural area, you may only have a few. To obtain a list of long-term care facilities in your area, contact your Regional Long-Term Care Ombudsman. Once you have a list of the options available in your area, focus only on the homes that provide the level of care that your loved one requires and that accepts the payment method you plan to use.

After narrowing your search based on level of care and payment method, here are some other considerations that will help you in the selection process:

- Research the facility's history of compliance with licensure rules. For Nursing Homes, you can find this information by visiting www.medicare.gov and clicking on Nursing Home Compare. For Adult Care Homes, you can find this information by visiting www.ncdhhs.gov/dhsr/ and clicking on Adult Care Facility Star Ratings.
- Gather input from trusted sources. Ask friends, neighbors, your physician, the hospital discharge planner and clergy members for their opinions about various facilities. They may be able to give you the name of a home where they have had first-hand experience.
- Consider the location of the facility. The closer your loved one is to friends, family and familiar places, the better. Try to select a facility that is conveniently located for family and friends to visit often.

- Contact any facilities that are being considered and take a formal tour. Talk to staff, residents, and family members if you can. Ask them if they are satisfied with the home and its services.
- Visit the facilities again – only this time, make an unannounced visit in the evening or on the weekend. This will give you a true picture of what life is like in the home.
- Trust your senses. Remember that the appearance of a facility is not as important as the quality of care and life.
- Whenever possible, be sure to include your loved one in the decision making process. Always keep their needs and feelings in mind.

The Admissions Process

Selecting a long-term care facility is a challenging process, but the journey doesn't end there. Once you've chosen a home, you must go through the admissions process which can be a daunting experience. The day of admission can be filled with forms, interviews, and tasks. Bringing along the following information on admission day will also speed up the process:



- Health care coverage information (including enrollment in medical insurance, long-term care insurance, Medicare, Medicaid, or Veterans benefits).
- A list of current and past health problems, surgeries, allergies and treatments.
- A list of special dietary needs and any food likes and dislikes.
- A list of current medications, including the dosage.
- A list of current doctors including names, addresses, and telephone numbers.
- A list of family members to call in case of an emergency.
- A copy of advance directives, if any exist.
- A copy of any legal documents naming a Financial and Health Care Power of Attorney, or a Guardian.

Be sure to give the staff insight into your loved one's likes, dislikes, routines, and preferences. The more the staff knows about your loved one, the more personalized care they can provide. This is the beginning of a "care plan" — the guide that tells the staff what kind of care and assistance each resident needs. Let the staff know what you expect from them.

One of the tasks you will face is figuring out the system and how it works. Don't be afraid to ask questions that matter to you or your loved one. Be sure you fully understand the facility's policies and procedures. Bring along a notepad and write down notes to ensure that you remember the important details. The more information you gather, the better equipped you'll be to help your loved one adjust to living in a long-term care facility.

After the Move



The move to a long-term care facility is more like a journey than an event for both the resident and the family. Once your loved one is living in a facility, your continued care, support, love, and involvement in his or her life are absolutely key to getting good care there. Make sure you:

- Visit frequently if possible and encourage others to visit.
- Attend quarterly care plan conferences (via conference call if you can't attend in person).
- Get to know the staff and help them get to know the resident.
- Participate in family council meetings if a family council exists, or seek out other family members to organize one.
- Speak up to share compliments and raise concerns.
- Contact the Regional Long-Term Care Ombudsman Program for assistance if you experience any unresolved problems or concerns regarding your loved one's care.

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